

AFFORDABLE LIFE-SAVING HEALTHCARE FOR CRITICALLY ILL CHILDREN

SECTION 1. STATEMENT OF FINDINGS AND DECLARATIONS

- (a) The California Children's Services (CCS) Program was established in 1927 and has provided life-saving health care to millions of critically ill children.
- (b) The CCS Program targets aid to children with eligible medical conditions, including cystic fibrosis, hemophilia, sickle cell disease, cerebral palsy, congenital heart disease, certain cancers, and traumatic debilitating injuries, among other serious medical conditions.
- (c) Over 200,000 California children receive life-saving specialized medical care from the CCS Program each year.
- (d) The success of the CCS Program is directly related to its focused approach through both of the following:
 - (1) Identifying very sick children eligible for the program as early as possible to provide life-saving medical care, to prevent long-term disability, and to provide both immediate and long-term specialized care to those children.
 - (2) Serving as the payer of last resort and providing financial assistance to families who are unable to pay for all of the specialized medical care needed for their child.
- (e) To improve access to, and the quality of, health care for these children, the people of the State of California hereby amend the CCS Program to accomplish all of the following:
 - (1) Align financial eligibility for the CCS Program with eligibility for subsidized coverage under the California Health Benefit Exchange, also known as Covered California, which was established pursuant to the federal Patient Protection and Affordable Care Act, as amended by the Health Care and Education Reconciliation Act (collectively, the "ACA").
 - (2) Right-size investments in CCS services and providers, to ensure the program is sustainable and accessible to children with life-threatening health conditions.
 - (3) Cover the costs of life-saving specialty drugs.

SECTION 2. AFFORDABLE LIFE-SAVING HEALTHCARE FOR CRITICALLY ILL CHILDREN

Sections 123831, 123832, 123833, and 123834 are added to the Health and Safety Code, and sections 123860, 123870, and 123875 of the Health and Safety Code are amended (deletions in ~~strikeout type~~ and additions in underlined type), to read:

§123831.

- (a) In addition to the medical conditions listed in Section 123830, the California Children's Services (CCS) Program shall provide services to children under 21 years of age with the medical conditions listed in Sections 41515.1 to 41518.9, inclusive, of Article 2 of Chapter 3 of Subdivision 7 of Part 2 of Division 2 of Title 22 of the California Code of Regulations, as those sections were in effect on January 1, 2022.

(b) Commencing no later than January 1, 2026, and every five years thereafter, the department shall consult with CCS medical directors and experts from the department's CCS technical advisory committees to consider the addition of other medical conditions to the list, by regulation.

(c) The department shall reimburse counties for the costs associated with an increase in CCS caseload resulting from the implementation of subdivision (b) during each fiscal year in which the costs are incurred.

§123832.

(a) In order to provide financial assistance to eligible middle-class families and to synchronize CCS benefits with the Affordable Care Act, consistent with the legislative intent for the CCS Program as expressed in Section 123825:

(1) Commencing on January 1, 2025, for a child who has an eligible medical condition under Sections 123830 or 123831, but who is not financially eligible for the CCS Program pursuant to subdivision (a) of Section 123870, the department shall provide financial assistance for excess out-of-pocket costs incurred by the child's family.

(2) For purposes of this section, the following definitions shall apply:

(A) "Excess out-of-pocket costs incurred by the child's family" are those costs incurred in a calendar year for medically necessary items or services to treat a CCS-eligible condition that exceed the individual out-of-pocket maximum. Such costs may be incurred due to non-coverage, limitations on coverage, or out-of-pocket costs (including coinsurance, copayment, and deductible obligations). Where costs are incurred for out-of-network items or services, such costs may contribute to the calculation of excess out-of-pocket costs incurred by the child's family only insofar as the department determines that such items and services were medically necessary on an out-of-network basis.

(B) "Individual out-of-pocket maximum" means the individual out-of-pocket maximum for in-network items and services for an individual-only silver plan under the Patient-Centered Benefit Plan Design adopted by the California Health Benefit Exchange, also known as Covered California, established pursuant to Section 100500 of the Government Code.

(b) The department shall establish a procedure for providing the financial assistance described in subdivision (a).

(c) Counties shall not have a share of the cost for the workload or financial assistance required by this section.

§123833.

(a) In order to ensure that children served by the California Children's Services (CCS) Program continue to have access to life-saving care, the department shall do all of the following:

(1) (A) On or before December 31 of each year, commencing on December 31, 2025, provide an annual Sustainability and Access Grant to each CCS-approved hospital. The grant shall be the product of two hundred dollars (\$200) and the combined sum of the hospital's total CCS outpatient visits and CCS inpatient days for the preceding calendar year.

(B) For purposes of this paragraph, the following definitions apply:

(i) "CCS-approved hospital" means a hospital that is approved by the CCS Program to provide services to a child enrolled in the CCS Program.

(ii) "CCS inpatient day" means a patient day for a CCS-enrolled child who has been admitted to an acute care hospital for a CCS-eligible condition, regardless of whether the day has been paid for by the CCS Program, the Medi-Cal program, or a Medi-Cal managed care plan.

(iii) "CCS outpatient visit" means a hospital-based outpatient visit or an emergency department visit by a CCS-enrolled child for a CCS-eligible condition, regardless of whether the visit has been paid for by the CCS Program, the Medi-Cal program, or a Medi-Cal managed care plan.

(C) (i) Grants received pursuant to subparagraph (A) shall be exclusively used to sustain and improve access to care and quality of care for CCS-eligible children.

(ii) Beginning on January 1, 2027, the department may conduct an audit of grant recipients biennially to confirm that the grants were used pursuant to the requirements of subparagraph (i).

(D) The grants described in subparagraph (A) shall not do any of the following:

(i) Constitute Medi-Cal payments or patient care payments.

(ii) Be offset by the state for any other purpose.

(iii) Be included in the calculation of low-income percent or the OBRA 1993 payment limitation, as defined in paragraph (24) of subdivision (a) of Section 14105.98 of the Welfare and Institutions Code, for purposes of determining payments to hospitals.

(E) The department shall establish a procedure for reporting CCS inpatient days and CCS outpatient visits pursuant to this paragraph.

(2) (A) With respect to payment rates for physician services that are lower than federal Medicare payment rates for the same or similar services, after accounting for all other adjustments required by law, adjust those rates to be no less than the federal Medicare payment rates for those same or similar services. Those adjusted rates shall apply only to services that meet all the following conditions:

(i) The services are provided to a CCS-enrolled child to treat a CCS-eligible condition.

(ii) The services are provided on or after January 1, 2025.

(iii) The services are among services to which physician reimbursement rates would apply if provided and covered under the fee-for-service component of the Medi-Cal program.

(B) The department shall review and adjust payment rates for physician services annually as necessary to comply with subparagraph (A).

(C) The adjustments and updates under subparagraphs (A) and (B) shall apply to both CCS payments made under the Medi-Cal program and CCS payments that are not made under the Medi-Cal program.

(D) The department shall adjust the payments to Medi-Cal managed care plans as necessary to implement this paragraph.

(3) (A) For a medically necessary life-saving specialty drug that is provided to a CCS-enrolled child for a CCS-eligible condition by a hospital on an inpatient basis, reimburse the hospital for the cost incurred by the hospital to acquire the drug. The reimbursement shall be paid separately from, and not be included as part of, any payment for inpatient services, including but not limited to payments made pursuant to Section 14105.28 of the Welfare and Institutions Code.

(B) For purposes of this paragraph, "life-saving specialty drug" means a drug, or a cellular or gene therapy product, that was added to the list of separately payable services, devices, and supplies through a Medicaid state plan amendment by the Department of Health Care Services prior to January 1, 2024, or a drug, or a cellular or gene therapy product, for which the United States Food and Drug Administration has: (i) granted Breakthrough Therapy Designation and (ii) granted approval for use on or after July 1, 2021.

(C) The department shall establish a procedure for reimbursements under this paragraph.

(D) This paragraph shall apply to both life-saving specialty drugs furnished to a CCS-enrolled child for a CCS-eligible condition reimbursed under the Medi-Cal program and life-saving specialty drugs that are not reimbursed under the Medi-Cal program but that are reimbursed directly by the CCS Program.

(E) Payments for life-saving specialty drugs as defined in subparagraph (B) that are provided to a CCS-enrolled child for a CCS-eligible condition, and that are provided or arranged by a Medi-Cal managed care plan, shall not be lower than the payments that would be made under this paragraph if the life-saving specialty drugs had been covered and reimbursed under fee-for-service Medi-Cal. The department shall adjust the payments to Medi-Cal managed care plans as necessary to implement this paragraph.

(b) The Director of Health Care Services shall seek all necessary federal approvals to obtain federal financial participation for payment adjustments and reimbursements described in paragraphs (2) and (3) of subdivision (a).

(c) Payments made pursuant to paragraphs (a)(1), (a)(2) and (a)(3) of this section shall be used to supplement existing funding and shall not be used to supplant or reduce any other financial obligations of the state or of a Medi-Cal managed care plan for services provided by a hospital or physician that receives such payments.

(d) Counties shall not have a share of the cost for the payments required by this section, regardless of CCS payer type.

§123834.

Notwithstanding any other law, any costs or increased payments associated with implementation of the provisions of "Affordable Life-Saving Healthcare for Critically Ill Children" shall not be funded using moneys derived from the tax imposed pursuant to Article 7.1 (commencing with Section 14199.80) of Chapter 7 of Part 3 of Division 9 of the Welfare and Institutions Code, or moneys derived from any subsequent or continued managed care organization provider tax imposed on or after January 1, 2027 for which the proceeds are used, in whole or in part, to increase reimbursement rates or payments under the Medi-Cal program or otherwise used to finance a portion of the nonfederal share of Medi-Cal medical assistance expenditures.

§123860.

In accordance with applicable regulations of the United States Children's Bureau, the department and designated county agencies shall provide a diagnosis for handicapped children. Within the limits of available funds, the department and designated local agencies may accept for diagnosis a handicapped child believed to have a severe chronic disease or severe physical handicap, as determined by the director, irrespective of whether the child actually has an eligible medical condition specified in Sections 123830 or 123831. The department shall cause a record to be kept listing all conditions diagnosed by the program and shall publish the information annually, including data on the number and kinds of diagnosed medical conditions that do not come within the definition of "handicapped child" as specified in Section 123830 or within the scope of Section 123831.

§123870.

(a) The department shall establish standards of financial eligibility for treatment services under the California Children's Services Program (CCS program).

(1) Financial eligibility for treatment services under this program shall include ~~be limited to~~ persons in families with an adjusted gross income of forty thousand dollars (\$40,000) or less in the most recent tax year, as calculated for California state income tax purposes. However, the director may authorize treatment services for persons in families with higher incomes if the estimated cost of care to the family in one year is expected to exceed 20 percent of the family's adjusted gross income. If a person is enrolled in the Medi-Cal program pursuant to Section 14005.26 of the Welfare and Institutions Code, or enrolled in the Medi-Cal Access Program pursuant to Chapter 2 (commencing with Section 15810) of Part 3.3 of Division 9 of the Welfare and Institutions Code, the financial documentation required to establish eligibility for the respective programs may be used instead of the person's California state income tax return. ~~However, the director may authorize treatment services for persons in families with higher incomes if the estimated cost of care to the family in one year is expected to exceed 20 percent of the family's adjusted gross income.~~

(2) Children enrolled in the Medi-Cal program pursuant to Section 14005.26 of the Welfare and Institutions Code or the Medi-Cal Access Program pursuant to Chapter 2 (commencing with Section 15810) of Part 3.3 of Division 9 of the Welfare and Institutions Code, who have a CCS ~~program~~ eligible medical condition under Sections 123830 or 123831, and whose families do not meet the financial eligibility requirements of paragraph (1), shall be deemed financially eligible for CCS program benefits.

(b) Necessary medical therapy treatment services under the California Children's Services Program rendered in the public schools shall be exempt from financial eligibility standards and enrollment fee requirements for the services when rendered to any handicapped child whose educational or physical development would be impeded without the services.

(c) All counties shall use the uniform standards for financial eligibility and enrollment fees established by the department. All enrollment fees shall be used in support of the California Children's Services Program.

(d) Annually, every family with a child eligible to receive services under this article shall pay a fee of twenty dollars (\$20), that shall be in addition to any other program fees for which the family

is liable. This assessment shall not apply to any child who is eligible for full-scope Medi-Cal benefits without a share of cost, for children receiving therapy through the California Children's Services Program as a related service in their individualized education plans, for children from families having incomes of less than 100 percent of the federal poverty level, or for children covered under the Medi-Cal program pursuant to Section 14005.26 of the Welfare and Institutions Code or the Medi-Cal Access Program.

§123875.

If the California Children's ~~Service~~ Services medical therapy unit conference team, based on a medical referral recommending medically necessary occupational or physical therapy in accordance with subdivision (b) of Section 7575 of the Government Code, finds that a handicapped child, as defined in Section 123830 or who has another eligible medical condition pursuant to Section 123831, needs medically necessary occupational or physical therapy, that child shall be determined to be eligible for therapy services. If the California Children's Services medical consultant disagrees with the determination of eligibility by the California Children's Services medical therapy unit conference team, the medical consultant shall communicate with the conference team to ask for further justification of its determination, and shall weigh the conference team's arguments in support of its decision in reaching ~~his or her~~ their own determination.

This section shall not change eligibility criteria for the California Children's Services programs as described in Sections 123830, 123831, and 123860.

This section shall not apply to children diagnosed as specific learning disabled, unless they otherwise meet the eligibility criteria of the California Children's Services.

SECTION 3. GENERAL PROVISIONS

- A. If any provision of this Act or application thereof to any person or circumstance is held invalid, that invalidity shall not affect other provisions or applications of the Act that can be given effect without the invalid provision or application, and to this end the provisions of the Act are severable.
- B. This Act is intended to be comprehensive. It is the intent of the people that in the event this Act or Acts relating to the same subject shall appear on the same statewide ballot, the provisions of the other Act or Acts shall be deemed to be in conflict with this Act. In the event that this Act receives a greater number of affirmative votes, the provisions of this Act shall prevail in their entirety, and all provisions of the other Act or Acts shall be null and void.
- C. The Legislature may amend this Act, except for section 123834 of the Health and Safety Code, to further its purposes by a bill passed in each house by rollcall vote entered into the journal, two-thirds of the membership of each house concurring. No statute amending, repealing, or adding to the provisions of section 123834 of the Health and Safety Code shall become effective unless approved by the electors in the same manner as statutes amending initiative statutes pursuant to section 10(c) of article II of the California Constitution.